

EMPIRICAL MANUSCRIPT

School-aged Children with Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Services, Experiences, and Outcomes

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Abstract

Following the establishment of newborn hearing screening programs, age of identification and length of time before receiving interventions has been reduced for children, including those with milder degrees of hearing loss who were previously not identified until school age. This population of early-identified children requires new support programs for parents. Although literature is emerging on how parents experience the initial years, there is limited information on support needs during early school years. The objectives were to gain insights into parents' experiences with services during the early period of identification until early school years, as well as their perceptions of the consequences of hearing loss on their child's overall development. A qualitative research design informed by Interpretive Description was employed. Individual semi-structured interviews were conducted with 12 parents of children identified with mild hearing loss. Transcripts were analyzed using a constant comparative method. Four themes emerged from the data: early experiences with services and hearing technology, effects of hearing loss on social functioning, effects of hearing loss on language and academics, and experiences in early school years. From parents' perspectives, more support during the early school years is needed to help ensure academic success.

Background

Early identification of permanent mild bilateral and unilateral hearing loss has become possible through newborn hearing screening programs (NHS). Hearing loss of all degrees of severity can have negative effects on language development, a vital health determinant for communication, academic performance and employability (Fischer & Lieu, 2014; Kyle & Cain, 2015; Purcell, Shinn, Davis, & Sie, 2016). Additionally, hearing loss also impacts family life, due to stressful treatment decision-making, expensive treatment costs, and family-child communication challenges (Quittner et al., 2010; Rivadeneira, Silvestre, & Laborda, 2015; Sarant & Garrard, 2014).

Although there is extensive literature discussing the consequences of moderate-profound hearing loss on language development, academic and social development, (Barnett, Gustafsson, Deng, Mills-Koonce, & Cox, 2012; Tasker, Nowakowski, & Schmidt, 2010) studies on the effects of mild bilateral and unilateral hearing loss on early-identified children are beginning to emerge. Studies report problems with speech and language development, localization, academic, and socio-emotional development (Fischer & Lieu, 2014; Purcell et al., 2016; Walker et al., 2015) although better understanding of the consequences is still required.

Prior to the implementation of newborn hearing screening programs, identification of mild bilateral and unilateral hearing

loss typically occurred through parental concern and often not before 4–5 years of age (Fitzpatrick, Durieux-Smith, & Whittingham, 2010; Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Ghogomu, Umansky, & Lieu, 2014). Following the establishment of screening programs, age of identification and length of time before receiving interventions for these children has been reduced (Holte et al., 2012; Durieux-Smith, Fitzpatrick, & Whittingham, 2008; Fitzpatrick, Whittingham, & Durieux-Smith, 2014; Ghogomu et al., 2014; Watkin & Baldwin, 2012).

This population of early-identified children with mild hearing loss requires consideration of support programs for parents, as early as infancy. Studies indicate parents feel overwhelmed upon receiving a hearing loss diagnosis, regardless of degree of severity (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Kurtzer-White & Luteran, 2003). In addition, parents are often emotionally unprepared for the lifestyle changes that follow the diagnosis. Comprehension of how hearing loss affects language development, what the rehabilitation requirements are, and how to incorporate language therapy into daily life is essential for optimal language outcomes. However, managing hearing technology has reportedly been very challenging for parents, even after prolonged amplification use (Fitzpatrick et al., 2008; Muñoz et al., 2015). An understanding of parental perspectives and experiences is needed for practitioners to provide effective services and support.

Although there is literature emerging on how parents of children with milder loss experience the initial years following the discovery of the hearing loss (Fitzpatrick et al., 2016; Lieu, Tye-Murray, & Fu, 2012), there is limited information on support needs of parents during the early school years. Additionally, research on mild bilateral and unilateral loss in the new context of newborn hearing screening is still limited and therefore, there is a need to understand parents' experiences to better tailor care and provide adequate support.

Context and Objectives

In Ontario, Canada, infants are screened for hearing loss at birth. Those who receive a refer result from screening are directed to diagnostic audiological assessments. Once a diagnosis has been made, parents discuss technology options with an audiologist. A family support worker meets with parents to discuss intervention options and available resources (e.g. financial support for hearing technology, community support, etc.). Intervention options typically involve spoken language approaches (e.g. oral), visual approaches (e.g. sign language), and total communication approaches (e.g. oral + sign). Parents decide on whether to use hearing technology and the type of intervention that aligns with their values. In the beginning, children are monitored at 3-month intervals or more to carefully monitor hearing and technology needs (Bagatto, Scollie, Hyde, & Seewald, 2010). Intensity of therapy interventions range according to need, from once a week to less frequent, depending on the child's functioning. All services are publicly funded.

In the context of this newborn hearing screening process, a study was initiated to explore auditory functioning, speech and language outcomes in children with mild bilateral and unilateral hearing loss during the early school years. One phase of the study utilized qualitative inquiry to explore parents' perceptions. Specifically, the objectives of this component of the study were to gain insights into parents' experiences with (or related to) services during the early period of identification until early school years, as well as their perceptions of the consequences of hearing loss on their child's overall longer term-functioning.

Methods

Design

A qualitative research design was employed to gain insights into parents' experiences during the early period of identification of their child's hearing loss as well as their perceptions regarding their child's functioning. The study design was informed by Thorne, Kirkham, and MacDonald-Emes (1997) Interpretive Description (ID) method. Drawing strongly on features of ethnography, naturalistic inquiry, grounded theory, ID attempts to generate a meaningful account of a clinical phenomenon, while also making it clinically accessible. Exploring parents' experiences requires methodologies that examine processes, diverse outcomes and various perspectives; qualitative techniques help capture such multilayered issues (Bradley, Curry, & Devers, 2007; Caronna, 2010).

Participants

Participants were selected from a group of parents of 15 children enrolled in an ongoing project, investigating communication outcomes in school-aged children identified with mild bilateral and unilateral hearing loss since the implementation of the NHS program in 2003. All parents in this group were approached. Participants selected for this study were all located in Ottawa, Ontario, the main study site. In the Ottawa area, preschool therapy services are provided at the pediatric hospital until school age, when interventions are incorporated into the public school system while audiological follow-up continues at the hospital.

Consistent with the larger study, we selected parents, whose children met the following inclusion criteria, to participate in the qualitative inquiry: (a) chronological age between 5 and 8 years at the time of enrollment, and (b) permanent mild bilateral or unilateral hearing loss.

Hearing characteristics were examined to ensure the inclusion of parents of children with different hearing profiles (bilateral, unilateral), as well as different ages to allow for multiple perspectives and experiences. Consistent with prior parent interview studies, a sample of 10–15 participants was anticipated to be a sufficient number for saturation where common themes could emerge from multiple perspectives (Kuzel, 1992). For the interviews, we contacted 15 families who indicated interest in participating in an interview through consent forms. Two families declined due to family circumstances and one was unable to be scheduled within the study timeframe, leaving a total of 12 parents who agreed to participate. Interviews with parents (11 mothers alone, 1 mother and father together) of 12 school-aged children were conducted.

Table 1 provides child characteristics and associated family education/income. Child characteristics are included solely for descriptive purposes. All parents had typical hearing and spoke English. All children were diagnosed in Ontario, with the exception of two who recently moved to the area. Six children had unilateral hearing loss and six had bilateral hearing loss. About 11 children underwent NHS, 4 of whom received a referral to diagnostic audiology following screening. Despite screening, the study group had a median age of confirmation of hearing loss of 39 months (interquartile range [IQR]: 5.1, 40.6). The later age of diagnosis reflects that 7 of the 11 children initially passed screening but returned to audiology at a later age. These children likely had late onset, progressive hearing loss, or very mild loss that was not detectable at initial audiological assessment. All children in the unilateral group had 40 dB HL or greater loss in

Table 1 Child characteristics and associated family education/income

Characteristics	Participants (n = 12)
Sex, n (%)	
Female	7 (58.3)
Route to confirmation of hearing loss, n (%)	
Screened	11 (91.7)
Passed	7 (63.6)
Referred	4 (36.4)
Age at confirmation (months), median (IQR)	39 (5.1, 40.6)
Onset of Hearing Loss, n (%)	
Congenital	2 (16.6)
Early onset ^a	2 (16.6)
Late onset ^b	7 (58.3)
Unknown	1 (8.3)
Hearing loss description, n (%)	
Unilateral	6 (50.0)
Bilateral	6 (50.0)
Type of hearing loss, n (%)	
Sensorineural	10 (83.3)
Mixed	1 (8.3)
Conductive	1 (8.3)
Amplification, n (%)	
Hearing aids	9 (75.0)
FM system only	2 (16.7)
No amplification (monitored)	1 (8.3)
Age of amplification (months), median (IQR)	37.6 (35.7, 49.7)
Etiology, n (%)	
Known	6 (50.0)
NICU graduate ^c	3 (50.0)
Hereditary/genetic	1 (16.7)
ENT malformation	2 (33.3)
Unknown	6 (50.0)
Age of interview (months), mean (SD)	109.8 (16.2)
Maternal education (years), mean (SD)	5.2 (3.1)
College/university, n (%)	12 (100.0)
Family income ^d , n (%)	
<80,000\$	9 (81.8)
>80,000\$	2 (18.1)

Note: Abbreviations: IQR = interquartile range; NICU = Neonatal Intensive Care Unit; ENT = Eyes Nose Throat.

^aEarly onset defined as onset by age 6 months.

^bLate onset: children who have passed screening and were later referred to audiology due to concern.

^cNICU does not include children with syndromic hearing loss or ENT anomaly.

^d11/12 families provided information on income.

the impaired ear. In the bilateral group, four of six had greater than 40 dB HL hearing loss in the worse ear. Nine children (75%) were fitted with hearing aids at a median age of 37.6 months (IQR: 35.7, 49.7), two received FM systems only, and one child with unilateral loss did not have a recommendation for amplification.

Etiology was known for 6 of the 12 children, with the largest number (n = 3) being children admitted to the Neonatal Intensive Care Unit (NICU). The children had hearing loss only, with no comorbid conditions.

Seven (58.3%) children were enrolled in weekly to monthly early intervention services from diagnosis to preschool years. At the time of the interview, children had a mean age of 9.1 years (SD:16.2), therefore most of the parents had over 5 years of experience with hearing loss. All but one child, who was enrolled in a private school, attended general classes in local

public schools. All of the mothers were well educated, having an average of 5.2 years (SD: 3.1) of post-secondary studies.

Ethical approval for the research was obtained from the Children's Hospital of Eastern Ontario Research Institute and the University of Ottawa.

Procedures: Interviews and Data Analysis

Based on the findings of our previous study with parents of preschool-age children with mild bilateral and unilateral hearing loss (Fitzpatrick et al., 2016), an interview guide was developed to guide conversations with parents. A semi-structured format was selected to guide the interview from a pre-determined list of questions (see Appendix). This format allows the flexibility of qualitative research in the form of open-ended questions. It also allows parents to comfortably describe their experiences and perceptions of their child's development. Meetings were conducted at the parents' home when possible or by telephone, depending on parents' preferences. Ten interviews were conducted in-person and two via telephone.

During the interview, we first asked parents how their child's hearing loss was identified. Questions regarding parents' needs immediately after identification, as well as in the years after the diagnosis of their child's hearing loss were then addressed. Finally, we inquired about parents' perceptions of their child's functioning. With consent, all interviews were audio-recorded. Field notes were recorded during and after the interviews to capture overall impressions and notable comments. The interviews were transcribed verbatim.

Child characteristics were collected from questionnaires sent to families at the time of enrollment for the larger study and were updated at 6 month intervals. This information was confirmed and supplemented with details regarding hearing loss such as age of identification, type, laterality, and intervention from the clinical chart. Questionnaires also captured information regarding parents' education, income, and intervention details.

Data Analysis

Quantitative data were stored and managed using the REDCap electronic data capture tool at the Children's Hospital of Eastern Ontario, Research Institute (CHXX RI). Descriptive analysis of characteristics collected were performed using Microsoft Excel. Consistent with qualitative research practices, transcription occurred concurrently with data collection as preliminary analysis informed future data collection. ID methodology commonly uses inductive data analysis techniques to identify topics of interest (Thorne, Kirkham, & O'Flynn-Magee, 2004). Corbin and Strauss' (2008) constant comparative method was used to guide the coding process, based on open, axial, and selective codes, an appropriate approach to analysis within ID methodology (Thorne et al., 2004). Transcripts and field notes were entered into NVivo (version 11.3), a qualitative software program used for coding.

Two researchers with expertise in audiology and rehabilitation performed open coding of all transcripts, which consists of studying and assigning labels to each passage. A comparison of the codes was done with a third researcher. This researcher verified the transcripts and confirmed the codes. Coding disagreements were resolved with modifications through discussion amongst the three researchers. All three researchers performed axial coding, which consists of refining and categorizing the concepts. Selective coding was then performed to further refine

the data by examining similar concepts and collapsing these categories into major themes. Notes and reflections were then consulted in finalizing key themes and all decisions were discussed amongst the three researchers.

Results

The goal of the interviews was to gain a deeper understanding of parents hearing loss service experiences and their perspectives of their child's development and academic functioning. As few differences emerged between children with mild bilateral and unilateral loss in the analysis, results were not separated on this basis.

Four themes emerged from the interview data: (a) early experiences with hearing loss, hearing technology, and services, (b) effects of hearing loss on social functioning, (c) effects of hearing loss on language and academics, and (d) experiences in early school years. The following section elaborates each theme with examples of parents' comments. Numbers in parentheses refer to study participant number.

Early Experiences with Hearing Loss, Hearing Technology, and Services

Adjusting to hearing loss

Several parents expressed appreciation for the NHS program and were pleased with the smooth route to diagnosis. However, seven parents reported that their children had passed newborn hearing screening and were later identified with permanent hearing loss leading to some frustrations in these situations:

"You know I keep thinking it's a shame we didn't catch it right away, it's a shame it wasn't caught at the hospital level... Yeah she screened totally normal, that they weren't able to detect I guess. So after a couple years I thought, as she was reaching two...I would notice she would lean forward with her left ear, and I would notice that she would read lips and she would really focus on lips". (P #16)

In discussing parents' needs following the diagnosis, several parents commented on a desire for more information on hearing loss:

"So some of the early on things that I thought that we needed, I was nervous, I was scared for her, my first thing was, I need to speak to somebody who is going to tell me as a parent that it is not my fault, it's not something that we brought her to, you know like a concert that was too loud- because you immediately take on that blame, you think: "Oh my goodness, what did I do to mess up my child for life now! For me it was education, I needed that education to set my mind at ease and then transition of being that positive parent, to talk to my now three year old and sort of take some time to get the hearing aid, and that she has to wear this thing potentially for the rest of her life". (P #16)

Parents also identified a preference for a presentation of all hearing loss technology options. They expressed a desire for more information in order to make an informed decision that aligns with their values:

"I would have liked for the different options to have been presented a little bit more neutrally. You can start with the FM system; there are also hearing aids as an option. Rather than, the way the hearing aids were presented as really the only option." (P #17)

"I was surprised that I wasn't offered anything to help out...to get her hearing out of her other ear better, like the BAHAs, the cochlear implants and stuff. Because she was doing so well, I guess maybe they didn't feel she needed it, she was adjusting..." (P #5)

Adjusting to hearing technology

As previously stated, most of the children (75%) used amplification. The hearing aid adjustment period was noted to be mostly smooth, though some parents described their children experiencing discomfort or having difficulties with keeping in the hearing aids. The majority of parents described noticing an immediate difference upon fitting of the hearing aids. All parents agreed that hearing aid use had made a positive difference. When asked about their child's perception of hearing aids, all parents reported positive experiences, ranging from the child accepting the aid to being excited about it. Many parents also had positive comments on FM system use at school and stated that their children enjoyed using them:

"You know, you'd be calling her for...she'd be watching TV in the other room, and you'd be calling her and she didn't respond... and then when we got the hearing aids later in the month, it was like night and day. It made a huge difference, yeah." (P #1).

"Then when he first put on the hearing aids, my watch actually banged against the table, huge noise, and he really paid attention like he whipped his head around to where the noise was coming from." (P #7).

"Oh [we noticed a difference] right away! Because she is in the French program, it really helped her with some of the words like, we speak English at home but French was a completely foreign language to her and she has never heard it so the hearing aid made a huge difference. If she didn't have the hearing aid she would have mispronounced some of the words or some of the letters." (P #19).

Perceptions of services

Experiences with clinical services were mostly positive, and clinicians were described as providing invaluable care where they addressed the needs of the family while also seamlessly setting up outside support (e.g. FM systems at school, itinerant teachers of the deaf and hard of hearing) and providing accommodations when required:

"I loved how CHXX [hospital program] set up the itinerant [specialist teacher]. It felt like everything fell into place. The itinerant was there the first day of school in grade one". (P #10)

"I felt like I couldn't have received better care for my child. I felt CHXX was a third member of our family because of how amazing they were for our family." (P #16)

Parents described the Auditory-Verbal Therapy (AVT) program as essential in that it provided tremendous support for their children:

"I think, the biggest thing was she went in and started that AVT with [practitioner's name] and that was fantastic in giving her a head start." (P #1)

"We were able to do auditory verbal therapy every Friday at CHXX [hospital]. And that helped him to learn to speak normally." (P #3)

The cost of private services was discussed extensively. Financial support for hearing technology was also reported to be a limitation that was of concern for optimal developmental outcomes:

"To be honest, if I could afford it, I would have him seeing someone...I would want him to have AVT several times a week because I feel like it really would have helped him with his speech...his words aren't clearly pronounced, and you know slurring instead of enunciating quite clearly. I remember in his preschool there was

another little boy who had hearing loss there and the father said that... I don't know if they had it 3 times a week or 5 times a week, and again the boy was quite young then and they said you can't quite tell at all when he speaks if there is hearing loss. So I always felt that that was... well I couldn't afford it of course, but that might have been a benefit to (child's name)...but just in terms of the reality that people who have more financial flexibility, their child will experience the benefit of that (amplification) in regards to hearing loss, but if you are lower income, or low income, that interferes with optimum benefit for your child." (P #6)

"Everything is really, really expensive and beyond our ability so it will be really nice if they accommodate this thing for us to help her become a normal kid to achieve her dreams." (P #15)

Occasionally, the lack of communication between services (e.g. hospitals, programs, schools, hearing aid dispensers) was a source of frustration for parents in terms of managing their child's healthcare. This resulted in several parents having to be strong advocates which required lots of time and effort:

"And then it confused me at the time the connection of it all. Does the left hand know that the right hand...you know what I mean, within the whole system... and I know that is a lot of effort to do, that's a lot of effort to try to make it a seamless system. Especially when you are dealing with different entities, it's trying to pull it together" (P #16)

Effects of Hearing Loss on Social Functioning

Many parents had no concerns regarding social functioning, however several parents expressed worries about interactions with peers and bullying. Interestingly, some of these parents had stated that initially peers were curious about their child's hearing aids and/or FM systems during kindergarten, which they viewed as positive. Events of bullying seemed to emerge in early grade school.

Hearing loss also affected choices of sports. Some parents described how they encouraged team sports as a social strategy:

"...there, hearing doesn't matter, everyone's kind of on the same field and I think that's good for her confidence to see that she can excel there, you know?". (P #2)

On the other hand, parents also expressed experiencing challenges with sports. Their children experienced difficulties due to the noisy environments, which can be overwhelming and impact their ability to concentrate on teammates and instructions. Some sports required children to remove their hearing aids (e.g. swimming or sports that result in sweating), which created participation barriers. Good strategies used by coaches in these events included verifying if the child understood the instructions.

In addition to sports, the majority of parents also commented on the effects of noisy environments on social interactions and how it often presented challenges for their children:

"You've got the kids all yelling and screaming and shouting at each other, and the echo bouncing off of the walls. She can't hear anything properly down there in that kind of a situation [school gym]." (P #5).

Effects of Hearing Loss on Language and Academics

While several parents felt their child had age-appropriate language, the majority (75%) felt their child's speech was affected by hearing loss. In addition, parents were worried their children

were lagging behind and expressed concerns regarding the effect of hearing loss on learning:

"I noticed that she wasn't pronouncing words the same way my other son who was about ...just about 13 months younger than her." (P #1)

"But she does, she sort of has trouble sometime saying her 's' clearly or her 'sh' sound or she'll drop some of the consonants sometimes at the ends of words. I think because she doesn't hear them herself so it's hard for her to remember to make the sounds when she's talking." (P #2)

"But then again, (child's name) now, with the damage [hearing loss] that he experienced to the learning centre of his brain, we certainly see how it manifests academically now." (P #6)

Notably, many parents also described how their child's hearing loss affected academics such as math, reading, writing, and learning French as a second language:

"Academically I think she is struggling a lot in math. We're not expecting a lot; I mean she is only eight right. But compare her to my son, who is in grade 1, he's doing much better than she is... She needs extra help with explaining the questions and one of the tests that she brought home, the teacher's like, I helped her with that." (P #15)

"One thing I think about a lot is French immersion because he really wants to do it and yet, I think it's a little bit harder for him because of the hearing loss...he's not pronouncing it as well as my other son..." (P #3)

Experiences in Early School Years

The majority of parents commented on how helpful it was to have itinerant teachers of the deaf and hard of hearing at their child's school. In particular, they commented on how wonderful it was to have someone check the equipment (e.g. FM systems) and instruct teachers on how to use it:

"The school was very accommodating...the teacher of the deaf for her school board has been with her since day 1. So she made sure that the amplification system was in her classroom and all the teachers were aware of her condition." (P #5)

Nearly half the parents reported an appreciation for the support received from schools. However, four parents felt differently, commenting on how more resources are needed and how as a result, they had to become advocates for their children:

"But I still had to push, like even last year. In kindergarten he saw an itinerant teacher for the hearing impaired there, and then he saw her in grade one too. But then next year she said he didn't need services anymore...And, when I learned later that (child's name) reading skills were very poor...I had to do that push and I am not good at that really...I was a little frustrated that it had been taken away because he can always benefit... that's what kind of confused me. It's not to say he can't benefit from the services or what the criteria other than being hearing impaired and struggling at school, it just didn't make sense." (P #6)

One parent described how she felt that because her child was doing relatively well, she was not able to receive additional support:

"I think...I understand that she's doing you know, well at school and there's other kids that need the resources more. So I do understand that. I sort of struggle with the concept that, you know, just because she's doing well, doesn't mean she necessarily couldn't use some extra help. Because in my mind, the goal for every kid

should be to have them meet their potential, not just to have them, kind of, doing the minimum best.” (P #2)

Some parents also observed a resistance from teachers to use hearing technology in the classroom. One parent commented that this was possibly due to teachers' perception of the effects of mild bilateral and unilateral loss:

“And he said that ‘oh well (child’s name) sits in front and can hear me, so I don’t want to wear it’. And I said yes well if you are facing the board and writing stuff it is harder for him to hear but I don’t know, he just didn’t want to wear it.” (P #3)

“She has one teacher who said she basically hears well and she doesn’t understand why she had to put the hearing aid [on].” (P #19)

Discussion

The goal of this study was to explore parents' experiences of services and perceptions of developmental and academic outcomes for school-age children with mild bilateral and unilateral loss. Our study expands on our previous research (Fitzpatrick et al., 2016) to include school-age children in order to gain perspectives on the transition into the early years of school. This study was also motivated from the previous study's finding that parents of preschool children expressed concerns about future academic functioning. The findings of our current study provide insight into parents' perceptions of their child's functioning, from hearing screening to early school years.

Parents appreciated newborn hearing screening programs, intervention services, and the support received from schools. Still, parents expressed they needed more information on hearing loss, amplification and intervention options. More long-term support during early school years was also desired.

Several findings in the current study are consistent with our previous research (Fitzpatrick et al., 2016). In both studies, screening was perceived positively by parents who were appreciative of having access to a screening program. In the current study, it was noteworthy that parents of children with later identified loss (e.g., late onset, progressive, not screened or mild loss not detected) wished their children had been able to benefit from earlier identification. Experiences of the early diagnostic process were generally quite positive in both studies, particularly with audiology and early intervention services. One difference that emerged in the current study was a need to be informed about all available hearing technology options.

Regarding amplification, in both our studies parents described witnessing an immediate difference following amplification. This finding highlights, from parents' perspectives, the benefits of amplification for children with milder forms of hearing loss. However, it is possible that this perspective arose as benefits are easier to observe in children with more developed language skills. In addition, measuring consistency of amplification use and the objective benefits of amplification was beyond the scope of this study. In past research, challenges of hearing aid use in children with milder loss and unilateral loss have been documented (Davis, Reeve, Hind, & Bamford, 2001; Fitzpatrick et al., 2016; Fitzpatrick, Durieux-Smith, & Whittingham, 2010; Walker et al., 2013). Regarding speech-language development, even with interventions, parents noticed their child's speech was affected by hearing loss. Parents in our previous study also expressed worries about the long-term effects of hearing loss on auditory and speech-language development (Fitzpatrick et al., 2016).

Literature investigating academic outcomes suggests that children with mild hearing loss are more likely to perform poorly in the early school years in comparison to typically developing children. Daud, Noor, Rahman, Sidek, and Mohamad's (2010) study on primary school children found a significant association between poor academic achievement and mild hearing loss. Lieu et al's (2012) longitudinal study on unilateral hearing loss reported teachers found academic achievement to be delayed in comparison to children with normal hearing. These findings align with some parents' perceptions in the current study of the negative impact of their child's hearing loss on multiple academic areas.

Recent studies on unilateral hearing loss have also indicated concerns about social problems for this population of children. Parents have reported problems with social functioning including a lack of social support, few friends, and that children avoid group settings such as parties (Borton, Mauze, & Lieu, 2010; Lieu et al., 2012). Our study lends support to these findings as many parents raised concerns about bullying.

Research on mild bilateral and unilateral hearing loss has mostly involved children identified at school age or later. The cohort in this study had access to screening at birth and several experienced early diagnosis and intervention, thereby contributing to this relatively new research field. Another strength of our study is that it provides one of the first accounts of parents' perceptions of the early diagnostic and intervention process in addition to the experience of the transition into school.

One limitation of this study was that the majority of the children had later identification of hearing loss. This characteristic was unexpected given the exposure to newborn screening, however at the time of recruitment, the majority of children in the study passed screening and were diagnosed well after the newborn period. Another limitation was that this study relied on parents' long-term memories, which introduces the possibility of recall bias. However, as the goal of this research was to explore parents' perspectives during the early period of identification and early school years, this limitation was unavoidable.

Given the limited research on parent needs during the screening to intervention process and the transition to school, our findings were able to provide insight into support requirements. Further research is still needed to best determine how to aid families of this new population of early-identified children with mild hearing loss. In addition, as our sample consisted of well educated families, it would be important to investigate the perspectives of parents from a range of socioeconomic levels.

The goal of early identification and intervention is to provide optimal language, social, and academic outcomes (Muse et al., 2013). In order to ensure optimal development, services need to provide adequate early support that meets the needs of parents of children with all degrees of hearing loss. From parents' perspectives, more support during the early school years is needed to help ensure academic success.

Funding

This research was supported by funding awarded to the second author from a Ministry of Health and Innovation's Early Researcher award, a Canadian Institutes of Health Research (CIHR) New Investigator Award and a Canadian Child Health Clinician Scientist Award.

Conflict of Interest

The authors have no conflicts of interest to declare.

Acknowledgments

We are grateful to the families who participated in this research and to the collaborating institutions that assisted with ethics requirements and patient recruitment.

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Appendix

Parent interview guide

Purpose of interview

I am meeting with parents to better understand the impact of the early identification of milder forms of hearing loss through infant hearing screening on the family. I will be talking with several parents of young children with hearing loss about their experiences with the identification of the hearing impairment. I would like to hear about how you learned of your child's hearing loss and how you think it has made a difference for you and your child and what your perceptions are of how your child is doing. I would also like to hear about your needs once you learned of the hearing loss and about what kind of services you feel were/are the most appropriate in guiding you in developing your child's communication.

Procedure

I will ask you questions to guide our conversation but feel free to talk about your experiences and to add any information you feel is important. Please do not hesitate to ask questions.

1. Tell me how you found out about your child's hearing loss.
*Probe: Tell me about the process from screening to confirmation of the hearing loss. How many visits?
 How long before there was a definitive confirmation?
 Did you have any concerns about your child during the process?*
2. Years ago, before newborn hearing screening was around, identifying hearing loss typically occurred around school age. Was learning about the hearing loss early on beneficial?
*Probe: How are things better/worse for you and your family because of the early diagnosis?
 How do you think it might be different if your child's hearing had not been screened?*
3. I am interested in understanding your needs when your child was first diagnosed and then later, in the early months/years after the diagnosis (e.g. preschool)?

Probe: What kind of information from service providers did you find helpful in the beginning?

What information or guidance did you need in the days/weeks/months following the diagnosis (for example, after the confirmation / hearing aid fitting)?

What kind of supports did you need, e.g. social worker, therapist, family?

What supports/information did you receive? What else was/is needed for you to help your child develop?

4. Tell me about your child's amplification.
*Probe: How was the adjustment?
 When is it used?
 Does your child ever comment on it?*
5. How are things going now?
*Probe: How are things with hearing aids? Does amplification make a difference - hearing /language?
 How was the transition to school?*
6. Tell us about how your child functions.
*Probe: Are there any situations/environments where you have observed things affected by his/her HL?
 Are there differences in speech/language, behavior, noisy environments, friends, at school, etc?*
7. What are your current needs and your child's?
*Probe: Do you have any concerns (e.g. about their development?)
 Do you need any support?*
8. Tell me about the services you have received for your child's hearing loss.
*Probe: Are you satisfied?
 Are your needs being met?
 What would you change?*
9. How does your child perceive his/her hearing loss?
*Does he/she ever talk about concerns or express frustration?
 Any positive or negative comments?*
10. Do you have anything else that you would like to discuss that was not covered?
Any recommendations?

General Information:

Location of interview: Home Other

Informant: Mother Father Other

Screening status: Screened UNHS Targeted Not screened

Screening category: Well-baby NICU At-risk No-risk

Age of child (interview) _____ Age at diagnosis _____
 _____ Age intervention _____

Degree of hearing loss: Mild Moderate Severe Profound

Hearing Technology: Hearing aids Cochlear Implant

Date of fitting _____ Date of Surgery _____

Diagnostic center _____

Intervention center(s) _____

Type of intervention _____

Frequency _____

Other disabilities _____

Interviewer Comments (use reverse side)